A Thesis Submitted for the Degree of PhD at the University of Warwick

Characterising, assessing and responding to the needs of adults with intellectual disabilities and adults with mental health problems

by

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Confirmation of contribution made by Jon Painter to publications to be considered as part of a PhD by published work

James, M., **Painter, J.,** Stewart, M. and Buckingham, B. (2018) ' A Review and update of the Health of the Nation Outcome Scales (HoNOS)', BJ*Psych Bulletin*.
Personal contribution to the publication: Was the sole NHS England representative on the ten-person international (i.e. Australia, New Zealand and the United Kingdom) Advisory Board which set project terms of reference, planned, collected and reviewed qualitative data from Health of the Nation Outcome Scales (HoNOS) trainers and clinicians from the three countries before producing an updated version of this mental health outcome measure. Personally collated information and redrafted 2 of the 12 scales for review by the group. Translated the lead author's narrative account of events into an acceptable academic style, including the formatting of references to the required style.
Co-authors' confirmation that the above is a true reflection of Jon Painter's contribution to the above publication:

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Personal contribution: Provided expertise in a key aspect of the subject matter (clustering) to help formulate the research question, identify the required routine data for extraction and analysis, interpret the results and contribute to drafts and re-drafts of the final paper.

Co-authors' confirmation that the above is a true reflection of Jon Painter's contribution to the above publication:

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Painter, J., Trevithick, L., Hastings, R., Ingham, B., and Roy, A. (2017) 'The extension of a set of needs-led mental health clusters to accommodate people accessing UK intellectual disability health services The extension of a set of needs-led mental health clusters to accommodate people accessing UK intellectual disability health services', *Journal of Mental Health*, Mar(2), ppp 1-9. doi: 10.1080/09638237.2017.1294737.

Personal contribution: Led on the design and coordination of the study, developing the research question, training the lead staff in each organisation in the use of the clinical measures used for validation purposes. Oversaw and contributed to the development and secure submission of a standardised dataset, all aspects (i.e. collation, analysis and interpretation) of the data management and the production of pilot, stage and final reports for NHS England. Independently developed complete first draft of the academic paper before incorporating suggestions and edits from co-authors. Submitted the final version to the relevant journal and produced re-drafts and responses to reviewer and editorial comments before again incorporating suggestions from co-authors.

Painter, J., Trevithick, L., Hastings, R., Ingham, B., and Roy, A. (2016) 'Development and validation of the Learning Disabilities Needs Assessment Tool (LDNAT), a HoNOS-based needs assessment tool for use with people with intellectual disability', *Journal of Intellectual Disability Research*, 60(12), pp. 1178–1188. doi: 10.1111/jir.12340.

Personal contribution: Led on the design and project management of the study, the development of the research question, training the lead staff in each organisation in the use of the required clinical measures.

Oversaw and contributed to the drafting and piloting of the additional scales that were subsequently added to the tool, the development of a standardised dataset, the secure submission process, collation, analysis and interpretation of the data submissions from individual organisations and the production of pilot, stage and final reports for NHS England.

Independently developed complete first draft of the academic output before incorporating views and edits expressed by co-authors. Submitted the final version to the relevant journal and produced re-drafts and responses to reviewer and editorial comments before again incorporating suggestions from co-authors.

Painter, J., Hastings, R., Ingham, B., Trevithick, L., and Roy, A. (in press) 'Identifying needs-based groupings among people accessing intellectual disability services', *American Journal of Intellectual and Developmental Disabilities.*

Personal contribution to the publication: Led on the design, coordination and day to day management of the study, the development of a suitable research question, selecting the additional measures required to validate the clusters, training the lead staff in each organisation in the use of the LDNAT and the other clinical measures required. Oversaw and contributed to the development of a standardised dataset, the secure submission process, collation, analysis and interpretation of the data submissions from individual organisations and the production of periodic progress reports for NHS England. Independently developed complete first draft of the academic output (journal article) before incorporating suggestions and edits from co-authors. Submitted the final version to the relevant journal and produced re-drafts and responses to reviewer and editorial comments before again incorporating suggestions from co-authors.

Painter, J., Trevithick, L., Hastings, R., Ingham, B., and Roy, A. (2017) 'Correlates for the risk of specialist ID hospital admission for people with intellectual disabilities: Development of the LDNAT Inpatient Index', *Tizard Learning Disability Review*, DOI: 10.1108/TLDR-04-2017-0015

Personal contribution to the publication: Led on the design and project management of the study, the development of the research question, training the lead staff in each organisation in the use of the required clinical measures. Oversaw and contributed to the development of a standardised dataset, the secure submission process, collation, analysis and interpretation of the data submissions from individual organisations and the production of pilot, stage and final reports for NHS England. Independently developed complete first draft of academic output before incorporating suggestions and edits from co-authors. Submitted the final version to the relevant journal and produced re-drafts and responses to reviewer and editorial comments before again incorporating suggestions from co-authors.

Painter, J., Hastings, R., Ingham, B., Trevithick, L., and Roy, A. (2018) 'Associations between mental health problems and challenging behavior in adults with intellectual disabilities: A test of the behavioral equivalents hypothesis.', *Journal of Mental Health Research in Intellectual Disabilities.*

Personal contribution to the publication: Identified the potential for secondary research to stem from this wider study. Led on the design and project management of the study, the development of the research question, selecting the validation measures training the lead staff in each organisation in the use of the required clinical measures. Oversaw and contributed to the development of a standardised dataset, the secure submission process, collation, analysis and interpretation of the data submissions from individual organisations and the production of pilot, stage and final reports for NHS England. Independently developed complete first draft of academic output before incorporating suggestions and edits from co-authors. Submitted the final version to the relevant journal and produced re-drafts and responses to reviewer and editorial comments before again incorporating suggestions from co-authors.

Co-authors' confirmation that the above is a true reflection of Jon Painter's contribution to the 5 publications above:

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I, Jon Painter, confirm that that this thesis has not been submitted for a degree at any other university

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Abstract

This thesis outlines a body of research relating to the concept of need and needs-led health service responses for people with intellectual disabilities (ID). In summary, it describes the content, linkages, strengths and limitations of seven published research papers, each with a different, but related focus/question about need.

The use of diagnoses in the field of mental health and ID is limited, leading some healthcare providers to adopt a more needs-based approach. Need, however, can be conceptualised in a variety of ways, each with its own benefits and drawbacks. Arguably the most objective of these are normative needs (i.e. a professional's assessment of an individual's need against a notional standard). This objectivity, combined with the limitations of diagnoses, has led some parts of the NHS to adopt normative needs-assessment as the basis of a new payment system.

Initially, the existing needs assessment tool was critiqued and recommendations for its improvement published. Outputs from the original tool's use (clusters of people with similar mental health needs) were also empirically confirmed to have logical relationships with the established diagnostic taxonomy.

Subsequently the tool was adapted and validated for use in specialist ID healthcare settings. Analyses of data resulting from this new tool's use identified statistically robust groups/clusters of individuals with similar severities and combinations of objective needs. These clusters were clinically recognisable and differed according to key features such as severity of ID, challenging behaviours, Autism symptoms and physical health problems.

Secondary analysis of these data then confirmed an existing clinical hypothesis i.e. that challenging behaviours in people with more severe ID may be viewed as behavioural manifestations of underlying mental health problems. Finally, these analyses suggested the normative needs assessment tool had utility in identifying users of community-based specialist ID services most at risk of admission to a specialist ID hospital.

1.0 List of abbreviations

Abbreviation	Full Term
AAIDD	American Association of Intellectual Disabilities
ADASS	Association of Directors of Adult Social Services
ADL	Activities of Daily Living
ANOVA	Analysis of Variance Analysis
ASD	Autistic Spectrum Disorder
ATU	Assessment and Treatment Unit
AUC	Area Under the Curve
b	Beta
BPI-S	Brief Problem Inventory for people with intellectual Disabilities-Short Form
BPI-Short Form	Brief Problem Inventory for people with intellectual Disabilities-Short Form
BSc	Batchelor of Science
CANDID	Camberwell Assessment of Needs for Adults with Developmental and Intellectual Disabilities
CB	Challenging Behaviours
CCG	Clinical Commissioning Group
C.F.	Conferateur (compare)
CI	Confidence Intervals
CSU	Commissioning Support Unit
DSM	Diagnostic and Statistical Manual
DF	Degrees of Freedom
DPP	Developmental Disabilities Profile
EG	Exempli Gratia (for example)
Et al	et alia (and others)
f	F-value
GP	General Practitioner
HEE	Health Education England

HoNOS	Health of the Nation Outcomes Scales
HRG	Healthcare Related Groups
HSD	Honest Statistical Difference
ICAP	Inventory for Client Agency Planning
ICC	Intra-Class Correlation
ICD	International Classification of Diseases
ID	Intellectual Disabilities
IDD	Intellectual Developmental Disorder
IE	Id Est (in other words)
I-CAN	Instrument for the Classification and Assessment of Support Needs
IP	Inpatient
IQ	Intelligence Quotient
j	Youden's Index
KMO	Kaiser-Meyer-Olkin
LD	Learning Disability
LDNAT	Learning Disability Needs Assessment Tool
MH	Mental Health
MHA	Mental Health Act
MHCT	Mental Health Clustering Tool
MHW	Mental Health and Wellbeing
MSc	Masters of Science
NB	Nota bene (note well)
NICE	National Institute for Health and Clinical Excellence
NIMHE	National Institute of Mental Health in England
NHS	National Health Service
NTW	Northumberland Tyne and Wear Mental Health NHS Foundation Trust
PbR	Payment by Results

PICU	Psychiatric Intensive Care Unit
PP	Pages
Para	paragraph
PAS-ADD Checklist	Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist
PCA	Principal Component Analysis
PH	Physical Health
r	Correlation coefficient
R&D	Research and Development
RMN	Registered Mental (Health Nurse)
RNLD	Registered Nurse for Learning Disabilities
ROC	Receiver Operating Characteristic
SCQ	Social Communication Questionnaire
SD	Standard Deviation
SIB	Self-Injurious Behaviour
Sig	Significance
SIS	Supports Intensity Scale
SPSS	Statistical Package for Social Sciences
t	T-statistic
TAG	Threshold Assessment grid
UK	United Kingdom
USA	United States of America
W-ADL	Waisman Activities of Daily Living Scale
X^2	Chi Squared
Yrs	Years

2.0 Introduction

This paper will explain the background to, content and quality of, and linkages between the seven articles that constitute this submission for a PhD by published work. For ease, the publications will be referred to according to the numbering in Table 2.1 below.

Following this introduction, the next section will provide the reader with the background information needed to contextualise the subsequent sections. The fourth section describes the objectives of each paper before the fifth outlines the range of research approaches and methods used. The sixth is an annotated bibliography of each paper and a formal critical appraisal of their quality. Having considered the publications individually, section seven synthesises their findings, explains their collective contribution and limitations before making recommendations as to how this work might be progressed. Section eight then provides some personal reflections on the heuristic process of doctoral study, before finishing with some brief conclusions.

Table 2.1: List of numbered publications

Paper No.	**Reference**
1	James, M., **Painter, J.**, Stewart, M. and Buckingham, B. (2018) ' A Review and update of the Health of the Nation Outcome Scales (HoNOS)', BJPsych Bulletin, 42(2), pp63-66.
2	Trevithick, L., **Painter, J.** and Keown, P. (2015) 'Mental health clustering and diagnosis in psychiatric in-patients.', BJPsych bulletin, 39(3), pp. 119–23.
3	**Painter, J.**, Trevithick, L., Hastings, R., Ingham, B., and Roy, A. (2016) 'Development and validation of the Learning Disabilities Needs Assessment Tool (LDNAT), a HoNOS-based needs assessment tool for use with people with intellectual disability', Journal of Intellectual Disability Research, 60(12), pp. 1178–1188.
4	**Painter, J.**, Trevithick, L., Hastings, R., Ingham, B., and Roy, A. (2017) 'The extension of a set of needs-led mental health clusters to accommodate people accessing UK intellectual disability health services', Journal of Mental Health, Mar(2), pp 1-9.
5	**Painter, J.**, Hastings, R., Ingham, B., Trevithick, L., and Roy, A. (in press) 'Identifying needs-based groupings among people accessing intellectual disability services', American Journal of Intellectual and Developmental Disabilities.
6	**Painter, J.**, Hastings, R., Ingham, B., Trevithick, L., and Roy, A. (2018) 'Associations between mental health problems and challenging behavior in adults with intellectual disabilities: A test of the behavioral equivalents hypothesis.' Journal of Mental Health Research in Intellectual Disabilities.
7	**Painter, J.**, Trevithick, L., Hastings, R., Ingham, B., and Roy, A. (2017) 'Correlates for the risk of specialist ID hospital admission for people with intellectual disabilities: Development of the LDNAT Inpatient Index', Tizard Learning Disability Review, 23(1), pp.42-50.

3.0 Background

This section provides an overview of the author's career as well as describing and exploring a number of the concepts integral to the publications that form the core of this thesis. These provide important context for the subsequent sections.

3.1 The Author

Qualifying as a Registered Learning Disability Nurse (RNLD) in 1996, I worked in a number of specialist NHS Intellectual Disability (ID) services across South Yorkshire. Drawn to working with people who exhibited challenging behaviours, I frequently encountered individuals experiencing concurrent mental health problems. Feeling ill equipped to deal with their complex needs, I undertook my Registered Mental (Health) Nurse (RMN) training, intending to return to ID services with an extended set of knowledge and skills.

After completing this second nursing qualification, instead of returning to ID services, I worked in a range of mainstream psychiatric rehabilitation services, eventually qualifying as a specialist nurse practitioner in psychosocial interventions for people with psychosis. Progressing into various management, clinical effectiveness and service improvement roles, I spent a significant amount of time systematically analysing healthcare processes and interventions. Often I was tasked with developing and implementing more efficient/effective care pathways which became the topic of my 2004 BSc dissertation.

From 2009 - 2016 I worked as the clinical lead for a regional consortium of mental health trusts that developed a needs-led approach to the classification of mental health service users. Together, we were instrumental in its uptake and mandated national use by all specialist NHS mental healthcare providers. Concurrently I worked at director-level in one of these trusts, leading a programme to rationalise and improve the quality of its clinical services by implementing the consortium's needs-led approach. My dual training, and split role, meant I was ideally placed to lead the work of a national group of specialist ID practitioners keen to blur the boundaries between traditional psychiatric and specialist ID services. The approach built upon, (rather than re-invented) the work of our mental health (MH) colleagues around needs-led service provision.

After the regional ID project and the local transformation programme ended, I took an academic post in Sheffield Hallam University. This coincided with the need to publish the project's outputs. It also provided the opportunity to complete an MSc in Health Informatics before using data from the consortium to produce several additional research papers.

In summary therefore, the work outlined in this thesis is the result of a firm belief in a needs-led approach to the care and treatment of people with mental health conditions and those with ID, as well as personal experience that suggested the needs of both these groups overlap significantly.

3.2 Defining mental illness and intellectual disability

Since the inception of psychiatry, a universally accepted definition for mental illness has proved elusive. Over time, a narrow, medicalised explanation of mental illness has been challenged by a range of other professions /stances including a psychological standpoint (Bolton, 2009) and a sociological perspective, typified by the recovery movement (Bonney and Stickley, 2008). Interestingly, the medical model has also received criticism from within, with some psychiatrists likening the profession to astrology and its professionals to malevolent social manipulators (Szasz, 1962). Articles, chapters and entire books have been written about this issue (e.g. Szasz, 1962; Busfield, 2011; Frances, 2013). However, to avoid detracting from its main focus, a more parsimonious approach has been taken in this thesis. As the publications all describe research undertaken in MH and ID healthcare settings, it follows that many staff involved advocate, or at least tolerate the use of psychiatric diagnoses. Therefore, whilst acknowledging the limitations of a purely medicalised explanation of mental illness (Widiger and Samuel, 2005), the papers in this thesis adopt Kendell and Jablensky's (2003) pragmatic stance by making a clear distinction between the validity and the utility of psychiatric diagnoses.

The latest Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and the draft version of the new International Classification of Disease (ICD-11) both define mental illness / disorder as:

> a syndrome characterised by clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour that reflects a dysfunction in the psychological, biological or developmental processes underlying mental function

(American Psychiatric Association, 2013, p30; WHO, 2017, section 6, para 1)

So, whilst this will undoubtedly remain a point of contention for some (e.g. First and Wakefield, 2010) it represents the working definition for mental illness employed throughout this thesis. Similarly, whilst there is a clear argument to suggest that mental illness and mental health are more accurately conceived as separate, but related continua (Westerhof and Keyes, 2010), the term 'mental health problems' is viewed as synonymous with 'mental illness/disorder'.

Conceptualisation of the term intellectual development disorder (IDD) has been through a similarly iterative process of refinement over many years (Schalock, 2011) and, like mental illness, remains a contentious term (Schalock and Luckasson, 2013). In this case, the debate largely centres around whether it is a health condition, or a cluster of disabilities (Salvador-Carulla *et al.*, 2011). Rather than being a purely semantic issue, the way in which ID is defined and identified can have significant practical implications for people requiring access to healthcare/funding (Schalock and Luckasson, 2013). Salvador-Carulla *et al.* (2011) explain that an ICD-11 international authoring party concluded that each of these polarised views offered advantages and disadvantages. They therefore advocated a compromise where diagnoses are complemented by subcategorisation of functional and personal characteristics and/or needs. ICD-11 provides little clarity in how these characteristics should be classified. However, its draft version defines disorders of intellectual development (IDD) as:

> a group of etiologically diverse conditions originating during the developmental period characterised by significantly below average intellectual functioning and adaptive behavior that are approximately two or more standard deviations below the mean (approximately less than the 2.3rd percentile), based on appropriately normed, individually administered standardised tests.
>
> (World Health Organisation, 2017 section 6, para 2)

It has though been suggested that, whilst the assessment of intelligence is integral to IDD, it also has limitations to both its measurement and its interpretation (O ’Brien, 2001). ICD-11 accommodates this viewpoint by acknowledging that, in the absence of formal IQ testing, IDD can also be diagnosed through clinical judgement of behaviour.

ICD-11's counterpart - DSM5 (American Psychiatric Association, 2013) uses the term intellectual disability (ID) but clearly states it is equivalent to IDD, defining it as:

> characterised by deficits in general mental abilities, such as reasoning, problem solving, planning, abstract thinking, judgement, academic learning, and learning from experience. The deficits result in impairments of adaptive functioning, such as the individual fails to meet standards of personal independence and social responsibility in one or more aspects of daily life, including communication, social participation, academic or occupational functioning, and personal independence at home or in community settings.
>
> (American Psychiatric Association, 2013b, p.31)

Further, as well as ID and IDD, in the UK, the term learning disability (LD) is also used for this construct (Schalock, 2011).

Finally, it is also important to note that conceptually, as with all diagnoses, ID and mental illness are not necessarily discrete, nor mutually exclusive (Kendell and Jablensky, 2003; Widiger and Samuel, 2005). In fact, whilst the exact prevalence of mental health problems in people with ID is unknown (Cooper *et al.*, 2007a) it is now generally accepted to be higher than in the general population (Bertelli *et al.*, 2015).

In summary therefore, mental illness and ID are complex, and often contentious terms, used to describe a wide range of presentations. Over time, narrow, medicalised definitions have been found wanting and hence expanded to align with a more holistic, biopsychosocial (see Engel, 1977) perspective. Nonetheless, these labels remain disadvantageous in today's society (Schalock and Luckasson, 2013) leading to calls for the traits, characteristics and needs of individuals to become part of the language routinely used by healthcare professionals and services (Salvador-Carulla *et al.*, 2011) rather than these other, more stigmatising labels.

3.3 Conceptualising needs and needs-led service provision

In mental health (MH) and intellectual disability (ID) healthcare, basing care, treatment, and services solely upon diagnoses can be problematic (Xenitidis *et al.*, 2000; Thompson *et al.*, 2004; Snell *et al.*, 2009). For example; the plurality of ways that two individuals with the same diagnosis can present makes diagnosis a poor predictor of service response (The Sainsbury Centre for Mental Health, 2004; Mason and Goddard, 2009). More fundamentally, the boundaries between, and indeed the diagnostic categories themselves, whilst having utility (Vieta and Phillips, 2007), are somewhat arbitrary, rather than empirically derived (Kendell and Jablensky, 2003; Widiger and Samuel, 2005; Shogren *et al.*, 2017). Consequently, as evidenced by multiple editions of the Diagnostic and Statistical Manual (DSM; American Psychiatric Association, 2013) and the International Classification of Diseases (World Health Organization, 1992), even the most established versions of ID and MH diagnostic taxonomies have limitations and remain subject to ongoing refinement.

As a result of these shortcomings, when striving for more responsive services and more individualised care/treatment plans, a growing number of specialist ID healthcare practitioners are adopting a needs-led approach (Parmenter and Riches, 2002). Need is, however, a complex term with no universal definition or even multi-professionally accepted understanding (Endacott, 1997; Asadi-Lari, Packham and Gray, 2003). In 1972, Bradshaw devised a conceptual taxonomy comprised of four types of needs: '**normative**' (a professional's assessment against a notional standard - e.g. against a standard of no impairment); '**felt**' (the individual's perception of their needs); '**expressed**' (the individual's request for help), and '**comparative**' (the difference between the individual's actual level of support and the norm). Despite significant advances in healthcare since its development, Bradshaw's seminal taxonomy remains largely valid today (McGregor, Camfield and Woodcock, 2009).

In the context of specialist ID healthcare, each of these ways of understanding needs has both advantages and shortcomings. Normative needs are the most objective but heavily reliant on 'expert' opinion and have been described by some as dismissive of the individual's own values and principles (McGregor, Camfield and Woodcock, 2009). Felt needs are highly subjective (Endacott, 1997) and thus viewed by some as the most pure/unfiltered description (McGregor, Camfield and Woodcock, 2009). Conversely, however, felt needs can be distorted by the individual's perception of their situation (Endacott, 1997) and (when translated into expressed needs) the individual's ability to articulate their requirements. Against these weaknesses, comparative support needs are seen as a highly pragmatic concept (Acheson, 1978), attracting interest in the field of ID

(Thompson *et al.*, 2004; Seo *et al.*, 2016). Nonetheless, comparative needs may be affected by the existence of effective interventions, and availability of services (Acheson, 1978; Asadi-Lari, Packham and Gray, 2003), inevitably leading to geographical variation in the type and/or intensity of services offered (McGregor, Camfield and Woodcock, 2009).

The starting point for needs-led service planning can, therefore, legitimately be the subjective or objective measurement of individuals' needs which are subsequently aggregated and translated into service (and resource) requirements. Conversely, available resources can first be translated into cost-effective services before the need for these services is used as the premise for individual assessments. These two perspectives are described by Acheson (1978) as the 'humanitarian' and 'realistic' approaches respectively. Whilst acknowledging the merits of both perspectives, the studies presented in this thesis utilise data from the objective measurement of normative needs in adults with ID and/or MH problems to inform needs-led service provision (i.e. they adopt Acheson's 'humanitarian approach' to the measurement of need). This is primarily due to the use of this approach in mental health payment systems within the NHS (described below).

3.4 Payment mechanisms in healthcare

Although arrangements are currently in flux (e.g. with the introduction of direct payments), National Health Service (NHS), MH and ID healthcare is traditionally delivered by providers who have met nationally defined quality standards (i.e. they are "approved"). These organisations range from small voluntary sector charities to large Foundation Trusts but (apart from a few exceptions), in England they are all commissioned by Clinical Commissioning Groups (CCGs). These GP consortia receive capitated budgets from NHS England to purchase cost-effective healthcare for their designated geographical area. However, due to the complexity of the resulting contractual arrangements, the negotiating, monitoring and performance management of these contracts is often undertaken by dedicated Commissioning Support Units (CSUs) on their behalf. In 2012, this multi-facetted approach to the commissioning and provision of specialist MH and ID healthcare in England was enshrined in the Health and Social Care Act 2012.

Beneath this commissioning model, different payment systems can be employed. Despite their diverse and complex nature, conceptually these should all merely be viewed as ways to incentivise the efficient delivery of high quality healthcare (Appleby *et al.*, 2013). The Kings Fund provides a helpful summary of these different payment systems (see Table 3.1).

Table 3.1: Description of Payment Systems (Appleby et al., 2013, P3)

Payment system	Description	Further description and examples
Block	Payment/lump sum for a specific – usually broadly defined – service independent of number of "patients"	For much of the life of the NHS, payment for hospital services was made in a single allocation, often supplemented by ad hoc payments, to support, for example, the establishment of new specialist services.
Capitation	Lump sum payment per patient/member of population served by a provider for comprehensive services or particular categories of service regardless of treatment	The majority of GPs' income (apart from those with employment contracts) consists of a payment related to the number of patients on their list (weighted by their age and other characteristics). The activities they are intended to carry out is defined in the GP national contract but only in very broad terms.
Pathway/ episode of care	Single payment to cover an entire episode/pathway of care	In the case of a pathway, payments may cover all the activities after initial identification of a problem or need from diagnostic investigation through to rehabilitation.
Case-based	Activity-based reimbursement per patient based prospectively on diagnosis/ patient characteristics	Under Payment by Results (PBR), payment for hospital services is made according to the number of individual procedures and other activities such as outpatient consultations. NB PbR has developed to include other payment forms and modifications
Per diem	Lump sum payment per patient per day of care regardless of consumption of care	Under Payment by Results, patients staying in hospital longer than the Healthcare Resource Group (HRG) trim point (the maximum expected length of stay) are paid for on a fixed per diem rate for each day above the trim point.
Fee for service	Activity-based (prospectively set) unit payment for a defined intervention regardless of patient characteristics	GPs' incomes are in part made up of fees for providing specified services such as vaccinations and inoculations.
Pay for performance	Payment linked to achievement of specific performance targets	The Quality and Outcomes Framework, which supplements performance capitation payments, is probably the largest scheme of this kind in the world. GPs earn extra payments if they provide specified levels of service.
Bundled payment	A single payment covering multiple elements of a patient's treatment	Bundled payments may involve the aggregation of different elements of care that were previously paid for separately – e.g., bundling consultants, drugs and diagnostic tests into a single outpatient payment, or bundling an inpatient stay with elements of care such as an operation and rehabilitation.
Unbundled	Separate payments for disaggregated elements of a patient's care	Unbundling payments for elements of care that were covered by a single payment previously may be allowed so that other organisations can provide some elements in the bundle (e.g., in the case of stroke, rehabilitation at home).
Mixed / blended systems	A combination of different payment methods	In practice payment systems may combine some or all of these systems. For example GPs are paid by a mix of capitation, fee for service and performance payments. Payment by Results has also developed to include a number of payment approaches.

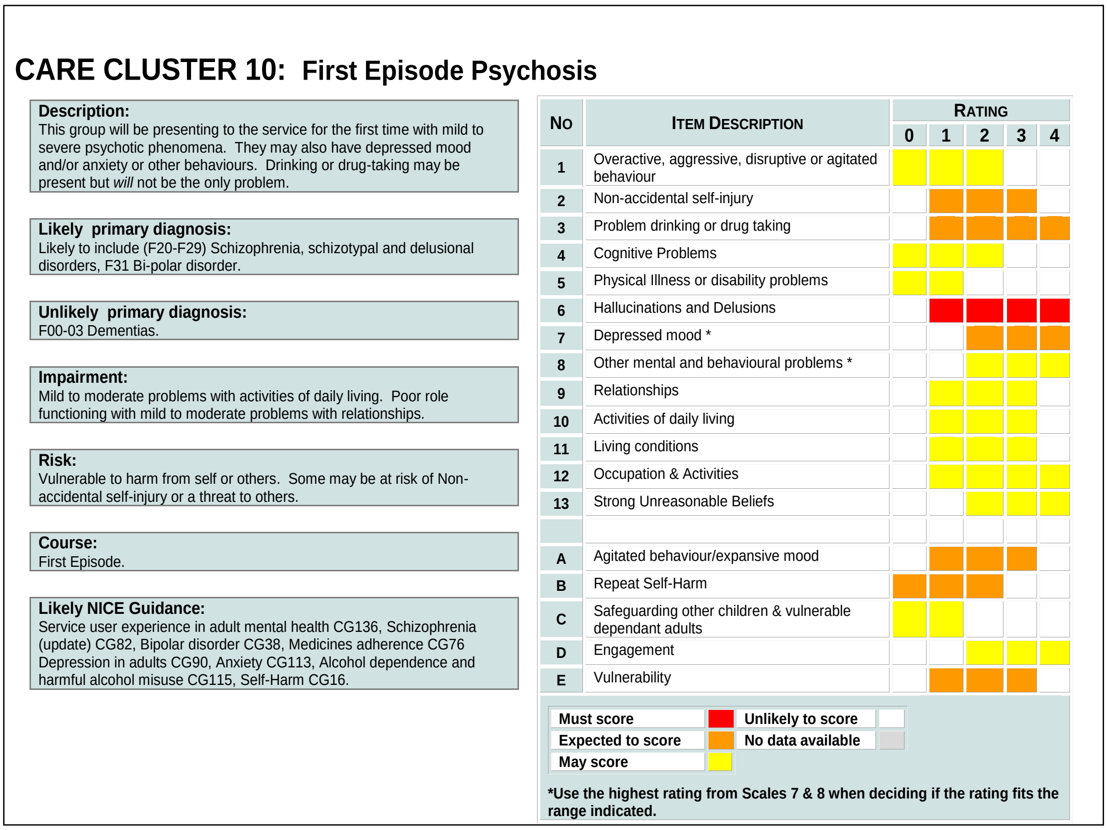
Since 2003/4 NHS specialist MH services have been making the transition from opaque block-contracts (Monitor, 2013) to a more outcome-based payment system, often referred to as Payment by Results or PbR (Department of Health Payment By Results Team, 2012). At its heart were data gathered from routine and regular use of the Mental Health Clustering Tool (MHCT). This needs assessment tool consists of the 12 Health of the Nation Outcome Scales (HoNOS; Wing, Curtis and Beevor, 1996) plus six additional scales, five of which are rated over a much longer time period. (Table 3.2; Department of Health, 2014).

Table 3.2: Summary of original MHCT scales and rating periods

Scale	Title	Rating Period
1	Overactive, aggressive, disruptive or agitated behaviour	Last two weeks
2	Non-accidental self-injury	Last two weeks
3	Problem-drinking or drug-taking	Last two weeks
4	Cognitive problems	Last two weeks
5	Physical illness or disability problems	Last two weeks
6	Problems associated with hallucinations and delusions	Last two weeks
7	Problems with depressed mood	Last two weeks
8	Other mental and behavioural problems	Last two weeks
9	Problems with relationships	Last two weeks
10	Problems with activities of daily living	Last two weeks
11	Problems with living conditions	Last two weeks
12	Problems with occupation and activities	Last two weeks
13	Strong unreasonable beliefs occurring in non-psychotic disorders.	Last two weeks
A	Agitated behaviour/ expansive mood	Open ended
B	Repeat self-harm	Open ended
C	Safeguarding Other Children & Vulnerable Dependent Adults	Open ended
D	Engagement	Open ended
E	Vulnerability	Open ended

Although diagnoses feature in most PBbR currency models (Mason and Goddard, 2009), to avoid problems arising from their 'loose' association with interventions, overlapping constructs and comorbidities (Widiger and Samuel, 2005) MH diagnoses were dismissed in favour of a more holistic biopsychosocial (Engel, 1977) taxonomy, as advocated by the Division of Clinical Psychology (2013). A nominalist approach to the classification of mental health conditions was therefore adopted i.e. that they can be grouped and organised in different ways, depending on the required purpose, a view supported by Zachar and Kendler (2007). A purpose-specific taxonomy was developed as the underpinning currency, i.e. stratified groups of patients with similar biopsychosocial needs and characteristics who require similar types of treatment for similar periods of time (Self, Painter and Davis, 2008).

These MH groupings were statistically derived through Ward’s method (Ward, 1963), followed by K-means cluster analysis of patient-level MHCT data. The resulting memberships were then adjusted by multi-disciplinary professional teams to ensure the final patient groupings were clinically, as well as statistically, homogenous (Self *et al.*, 2008). Subsequently, the clusters have been augmented with vignettes and other clinical information to aid accurate patient allocation by any mental health professional (See: Figure 3.1, and Department of Health, 2014).



CARE CLUSTER 10: First Episode Psychosis

Description:
This group will be presenting to the service for the first time with mild to severe psychotic phenomena. They may also have depressed mood and/or anxiety or other behaviours. Drinking or drug-taking may be present but *will* not be the only problem.

Likely primary diagnosis:
Likely to include (F20-F29) Schizophrenia, schizotypal and delusional disorders, F31 Bi-polar disorder.

Unlikely primary diagnosis:
F00-03 Dementias.

Impairment:
Mild to moderate problems with activities of daily living. Poor role functioning with mild to moderate problems with relationships.

Risk:
Vulnerable to harm from self or others. Some may be at risk of Non-accidental self-injury or a threat to others.

Course:
First Episode.

Likely NICE Guidance:
Service user experience in adult mental health CG136, Schizophrenia (update) CG82, Bipolar disorder CG38, Medicines adherence CG76 Depression in adults CG90, Anxiety CG113, Alcohol dependence and harmful alcohol misuse CG115, Self-Harm CG16.

No	Item Description	Rating				
		0	1	2	3	4
1	Overactive, aggressive, disruptive or agitated behaviour	🟨	🟨	🟨		
2	Non-accidental self-injury		🟧	🟧	🟧	
3	Problem drinking or drug taking		🟧	🟧	🟧	🟧
4	Cognitive Problems	🟨	🟨	🟨		
5	Physical Illness or disability problems	🟨	🟨			
6	Hallucinations and Delusions		🟥	🟥	🟥	🟥
7	Depressed mood *			🟧	🟧	🟧
8	Other mental and behavioural problems *			🟨	🟨	🟨
9	Relationships		🟨	🟨	🟨	
10	Activities of daily living		🟨	🟨	🟨	
11	Living conditions		🟨	🟨	🟨	
12	Occupation & Activities		🟨	🟨	🟨	🟨
13	Strong Unreasonable Beliefs			🟨	🟨	🟨
A	Agitated behaviour/expansive mood		🟧	🟧	🟧	
B	Repeat Self-Harm	🟧	🟧	🟧		
C	Safeguarding other children & vulnerable dependant adults	🟨	🟨			
D	Engagement			🟨	🟨	🟨
E	Vulnerability		🟧	🟧	🟧	

Must score	🟥	**Unlikely to score**	⬜
Expected to score	🟧	**No data available**	▨
May score	🟨		

***Use the highest rating from Scales 7 & 8 when deciding if the rating fits the range indicated.**

Figure 3.1: Example cluster profile (Department of Health, 2014) combining typical MHCT scoring profiles and case characteristics

Divided into three classes (labelled psychosis, non-psychosis and organic) the current MH taxonomy consists of 21 ‘clusters’, each with a specified combination and severity of patient-needs, as rated using the MHCT. In the future, it is possible that this case-based payment system could be supplemented by an element of performance related payment to create a blended payment system (Appleby, 2013) to incentivise effectiveness as well as efficiency.

Papers 1 and 2 in this thesis describe research into the original MH model. Despite not leading their write up, they have been included in this thesis as its author was heavily involved in both projects. Additionally, they form an important prelude to the ID-focused research Papers (3-7) described in this thesis that were all led by its author. These later papers stemmed from a multi-disciplinary group of specialist ID healthcare professionals recognising the applicability of the MHCT (Self *et al.*, 2008) to the measurement of their clients' needs and hence setting about improving its utility for people with ID. The next section details the specific research questions that were formulated to forward this broad research problem.

4.0 Research objectives

Clear research objectives translate broad problem areas into well-defined, answerable research projects (Grove, Gray and Burns, 2015). This thesis includes seven publications, each concerned with the general topic of: the measurement of needs and needs-led specialist service provision for people with ID. Their specific objectives are summarised below (Table 4.1).

Table 4.1: Research objectives of each publication.

Paper	Summarised Objective(s)
1	To improve rater experience by removing ambiguity and inconsistency in the rating glossary of the HoNOS (rather than a full redevelopment and revalidation).
2	a) To investigate the clinical utility of the advice in the MHCT booklet regarding likely and unlikely diagnoses by analysing the diagnostic make-up of each cluster. b) To investigate the distribution of diagnoses across both superclass and individual cluster groupings.
3	To extend an existing mental health needs assessment tool to create a new tool suitable for use in both MH and ID services as a broad assessment of need for people with ID.
4	To extend the mandated needs-based mental health clusters to accommodate the additional needs of people typically accessing specialist UK ID health services.
5	To apply cluster analysis techniques to identify normative needs-based groupings of adults with ID referred to specialist ID services in the NHS
6	To explore the putative association between mental health problems and challenging behaviours by testing the hypothesis that challenging behaviours are behavioural equivalents of mental health problems.
7	To investigate the validity of using items from the Learning Disability Needs Assessment Tool (LDNAT) as a risk indicator of admission to secondary care ID hospitals in the UK.

The first two objectives stemmed from this author's national role developing the MH payment system described in section 3.4. Objectives 3 and 4 were the result of discussions with ID practitioners and securing funding from NHS England for a multi-site study to extend the MH work into ID services. Papers 5 and 6 had more theoretical objectives, free from the constraints of sponsored project aims. These primarily academic endeavours flowed from questions that arose naturally whilst working closely with the data from the earlier papers. The final objective (7) was an attempt to 'give something back' to the staff who had participated in the studies. They were all challenged by the national diktats to close specialist inpatient beds for people with ID (Transforming Care Steering Group, 2014). This seventh paper was an attempt to use the data that had been gathered to provide a tangible answer to one part of their plight i.e. who, on their caseload, was most in need of proactive community support. The next section provides an overview of the research methods used for each objective.

5.0 Methodology

This section outlines both the overall approach, and the specific research methodologies employed in each of the seven papers.

5.1 Overarching process and approach

Figure 5.1 (below) depicts the four main data collection/analysis exercises, together with the associated outputs from each.

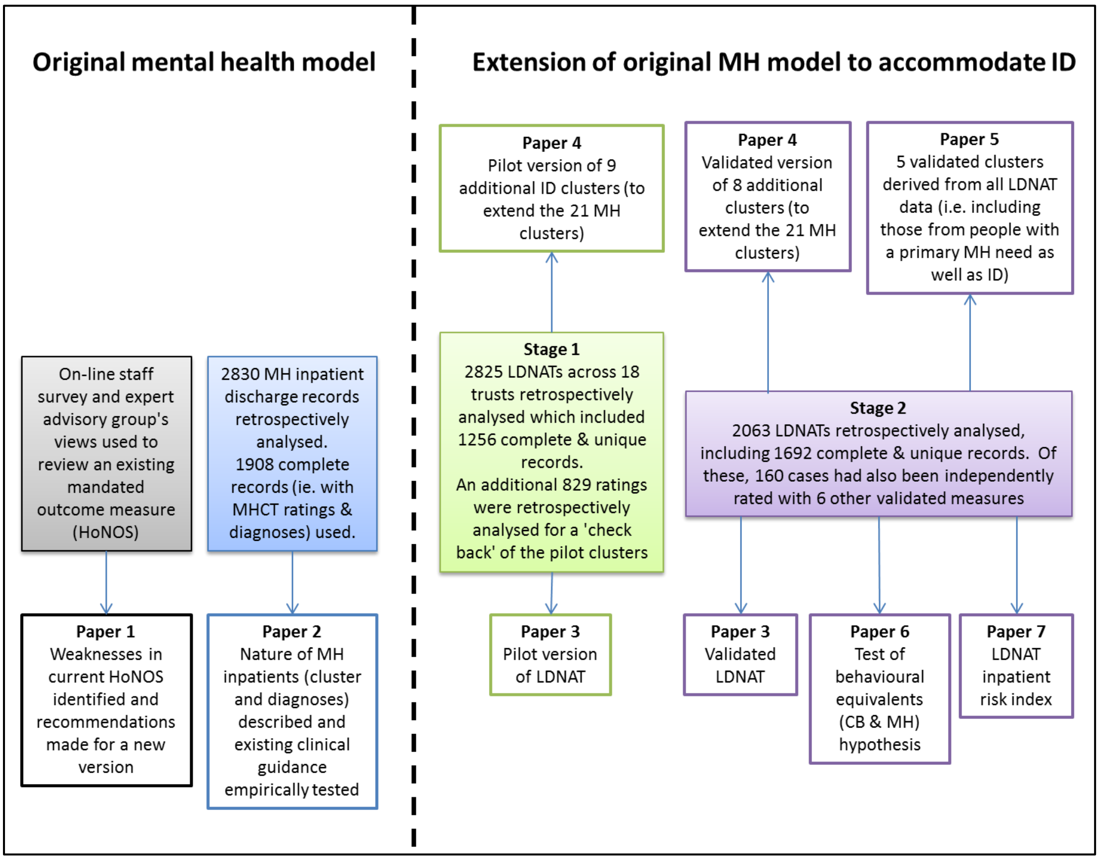


Figure 5.1 Data collection phases and respective outputs

Although the work falls into two distinct parts, each with a number of stages and outputs, the broad overarching approach is one of empiricism, i.e. the observation/collection and description of verifiable information (Feldman and Millor, 1994). Equally the entire body of work is firmly seated within the field of applied/practical research as it clearly seeks to positively influence clinical practice (Grove, Gray and Burns, 2015, p35)

Research is typically subdivided into qualitative and quantitative approaches, each with numerous potential methodologies. The two investigations into Self *et al's.* (2008) original mental health module were relatively straightforward and completely independent of each other, one being purely qualitative and the other purely quantitative. However, extending the work to accommodate the needs of people with ID required a more complex, staged approach. In both parts of this work, statistical validity had to be balanced with clinical utility and face validity. As a result of this additional complexity a mixed methods approach was adopted, thus exploiting the strengths of both qualitative and quantitative methodologies (Grove, Gray and Burns, 2015, p243).

Historically a hierarchy of evidence favoured quantitative methods (see Sackett, 1966). However, it is now generally accepted that the aims and objectives of projects should dictate their design (Gray, Grove and Sutherland, 2017, p25). In this way, each method can be viewed as a tool for the researcher to appropriately select and use according to the task in hand. The specific methods employed in these seven studies are summarised in Table 5.1. When read in conjunction with Table 4.1these show how methods were matched to objectives.

Paper 1, for example, adopts a qualitative approach to understand clinician's perspectives (as advocated by Green and Thorogood, [2018, p53]). Specifically, it gathered views internationally from clinicians via online communication, as recommended by Green and Thorogood (2018, p237) when recruiting dispersed and/or highly specialised participants. Also, appointing an expert advisory panel of interested experts fits Webb's (1996) definition of action research i.e. empowering participants to take control of, and solve practical problems. Finally, Delphi techniques (as employed by the expert Advisory Panel) are, according to Cormack and Benton (1996), a helpful way to rank qualitative data.

The quantitative studies (Papers 2-5) were all concerned with relatively new measures (the MHCT and the LDNAT) and analysing the resulting data. Where little is known about a topic and the primary objective is to portray the characteristics of a sample, Gray, Grove and Sutherland (2017, p28) advocate descriptive designs. They also recommend these as helpful pre-cursors to correlational studies, which investigate relationships between variables identified from theory/practice (McQueen and Knussen, 1999, p59). Logically, therefore, the final two papers consider relationships between variables in the dataset i.e. mental health problems and challenging behaviours (Paper 6), then severity of need and hospital admission (Paper7).

Table 5.1: Research approaches, designs, analysis techniques used

Paper		**1**	**2**	**3**	**4**	**5**	**6**	**7**
Research approaches	Qualitative	X						
	Quantitative		X			X	X	X
	Mixed methods			X	X			
Study designs	Action research	X		X	X			
	Descriptive/exploratory research		X	X	X	X		
	Correlational research						X	X
Quantitative research techniques	Descriptive statistics		X	X	X	X	X	X
	Chi^2 test		X					
	Principal Components Analysis			X				
	Cronbach's alpha			X				
	Intra-class correlation coefficients			X				
	Pearson correlation coefficient			X			X	
	Kaiser-Mayer-Olkin			X				
	Ward's method cluster analysis				X	X		
	K-means cluster analysis				X	X		
	ANOVA				X	X		
	Independent t-tests				X			X
	Post-hoc Tukey test					X		
	Moderated multiple linear regression						X	
	Receiver Operating Characteristic							X
	Mann-Whitney U test							X
	Youden Index							X
	Sensitivity/specificity tests							X
Qualitative research techniques	Surveys	X						
	Focus groups			X	X			
	Informal Delphi method	X						

Overall therefore, the production of the papers in this thesis required understanding of, and competence in, a wide range of quantitative and qualitative research methods. These were selected to address seven specific objectives, each inspired by the findings and learning of the previous studies. The next section provides an annotated bibliography of these papers.

5.2 Ethical Considerations

All direct and indirect nursing activity should be ethically sound (Nursing and Midwifery Council, 2015) which, by default, includes all aspects of clinical governance. Consequently, all data used in the seven papers was psedonymised prior to being sent to the research team. Additionally, data was encrypted to NHS standards prior to transmission across secure (N3) connections. In this way confidentiality and security of data was fully safeguarded in line with all relevant research standards.

Service evaluation is typically viewed by patients as an integral aspect of quality assurance, however 'pure research' can pose additional risks, over and above routine treatment and hence requires additional safeguards (Health Research Authority, 2009). Distinguishing between service evaluation and research can though be difficult (Twycross and Shorten, 2014) and so the Health Research Authority has provided additional guidance. They suggest four key discriminants:

1. Intent (research aims to produce generalisable new knowledge whereas service evaluation seeks to measure existing care/treatment).
2. Treatment (Research can utilise novel approaches whereas service evaluations involve established procedures).
3. Allocation (In service evaluation, any treatment is collaboratively decided by the patient and clinician)
4. Randomisation (in contrast, research can involve randomised allocation to treatment).

Additionally, where projects have multiple aims, the primary aim should be used to define their nature (Health Research Authority, 2009). With these points in mind the body of work featured in this thesis, as depicted in section 5.1 was deemed to be service evaluation, a decision that was confirmed by the Author's Trust Research and Development Lead.

6.0 Overview and appraisal of the author's publications

This section briefly outlines each of the papers at the core of this thesis, including their place in the wider literature, their objectives, main findings and limitations. As described previously, their sequence, in many ways reflects the author's heuristic journey through the concepts of need and needs-led service provision. Thus there is a logical progression from research into the original MH model, through its adaptation for ID services, explorations of the groupings of need that existed within the resulting data, to the development of practical applications of the approach which were specific to ID services and their service users. This is represented diagrammatically below.

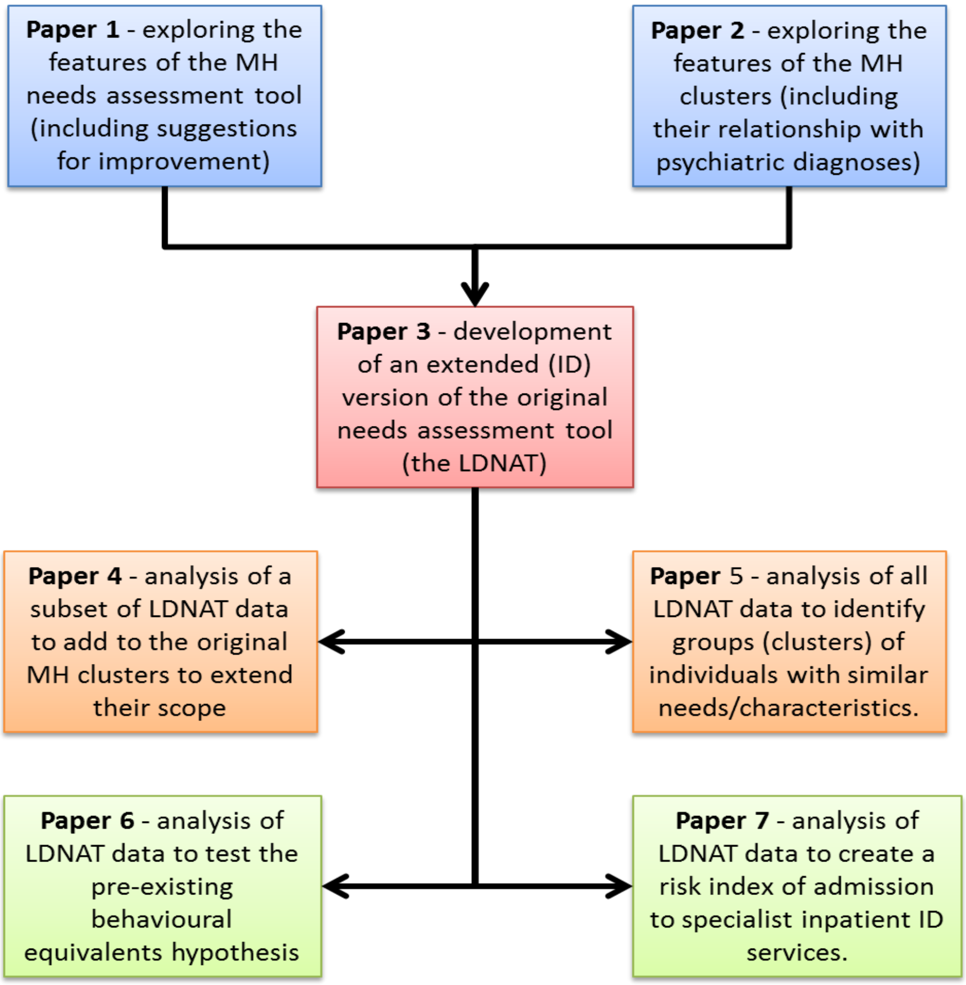


Figure 6.1: Relationships between papers

6.1 James, M., Painter, J., Stewart, M. and Buckingham, B. (2018) ' A Review and update of the Health of the Nation Outcome Scales (HoNOS)', BJPsych Bulletin.

HoNOS (Wing, Curtis and Beevor, 1996a) is a 12-item clinical measure that measures individual patient health and social care outcomes to guide the care/treatment of individuals experiencing mental health problems (Wing, Curtis and Beevor, 1996b). As described in section 3.4, HoNOS has also been widely used in the UK to identify patient needs at the outset of treatment and is included in the National Institute of Mental Health in England's (NIMHE) Mental Health Outcomes Compendium as one of several 'general [mental] healthcare needs assessments'. However, despite the plurality of alternatives, HoNOS is currently the only measure of need mandated for all UK specialist mental health providers. As such, its significance within the UK's mental healthcare is well established and, after more than 20 years of use, this is the first paper to propose an update in any detail.

The study's aim was to describe the structured consensus-building approach adopted to update the rating glossary of the HoNOS (which provides much of the data used in Papers 2-7). A qualitative design was appropriately selected as the project sought to use structured expert opinion (see Grove, Gray and Burns, 2015, p66) to improve the utility of the HoNOS in contemporary mental healthcare prior to empirical reliability and validity testing.

Due to the tool's international usage, the politics and agendas of multiple influential stakeholders required careful management. Hence, the three governments that have mandated its use (Australia, New Zealand and England) were invited to nominate representatives. The resulting 13-person Advisory Panel members each had sufficient clinical experience of the HoNOS to make credible judgements, the ability to advocate for their respective country, and to collectively constitute an effective project team (Cohen and Bailey, 1997). Given these panellist's influential status, potential participant bias was mitigated by asking them to canvas widely for the views of other HoNOS trainers and healthcare professionals experienced in using HoNOS in clinical practice as well as providing pertinent published research. Additionally, they produced (and reported on) a set of explicit criteria, against which each proposed amendment would be judged. The collated feedback regarding each HoNOS scale was reviewed by the Advisory Panel and used to produce an improved glossary through a series of teleconference calls aided by Delphi techniques (Cormack and Benton, 1996). The paper included the new version of the glossary, the original wording, and the rationale for each change.

Some of this paper's limitations resulted from the journal's word limit (e.g. the brevity of the introductory overview of the current research into HoNOS). Others arise from the politically sensitive nature of the project (e.g. imbalance of representation from each country on the Advisory Panel). However, overall this paper provides sufficient information to judge the trustworthiness (Grove, Gray and Burns, 2015, p392) of a subjective process which had significant implications for numerous stakeholders and hence was potentially contentious (Lee, 1993, p3).

On a more personal level, undertaking this detailed analysis with a group of international experts provided a thorough understanding of the strengths, weaknesses and idiosyncrasies of HoNOS (summarised in the paper). This proved invaluable when adapting it for use in the over-arching project that culminated in this thesis. For example, appreciating that some HoNOS scales explicitly excluded behaviours attributable to ID helped guide the development of the additional scales in the extended version of the tool (Paper 3). Similarly, when developing training materials (Paper 3) it was helpful to know staff's perceptions (and misconceptions) about each scale.

6.2 Trevithick, L., Painter, J. and Keown, P. (2015) 'Mental health clustering and diagnosis in psychiatric in-patients.', BJPsych bulletin, 39(3), pp. 119–23.

The clustering process described in section 3 only became widely used following its mandating in 2013. Consequently, at the time of writing Paper 2, there was a dearth of published research into the approach. Therefore, the main aim of this study was to describe the diagnostic make-up of each needs-based cluster for 12 months' worth of psychiatric inpatient admissions to a large NHS mental health trust. Also, in the absence of any published mappings of this nature, a secondary aim was to compare empirical results to the guidance published by NHS England that had been solely derived through expert opinion (Department of Health, 2014). To meet these aims a retrospective quantitative analysis of data was undertaken, as advocated by Grove, Gray and Burns (2015) when little is known about a topic.

In essence, the paper was an exploration of the routinely recorded data in 2,830 electronic patients' records primarily using descriptive statistics. Interestingly, however, this basic analysis revealed that, despite their far more recent development, 91% of patients were allocated to a cluster within 3 days of admission whereas only 74% received a formal diagnosis by their discharge. When each taxonomy was considered individually, the spread of diagnoses or clusters was largely unremarkable. More interesting were the cross-tabulated results as these provided insight into the variation in need for each diagnostic grouping (and vice versa). Overall, there was a logical relationship between broad diagnostic groupings such as "Organic, including symptomatic, mental disorders" (F00-09); "Schizophrenia, schizotypal and delusional disorders" (F20-29) etc. and each MHCT super cluster (psychosis, non-psychosis, organic). However, "mental and behavioural disorders due to psychoactive substance use" (F10-19) diagnoses, in particular, complicated the mapping by appearing in numerous clusters. The cross-tabulated results also supported a previous hypothesis that bipolar affective disorder legitimately mapped to multiple clusters, (depending on the phase of illness). These results were then compared to the published expert opinion on 'likely' and 'unlikely' diagnoses for each cluster. In 11 of the 17 clusters analysed, the clinical advice regarding 'likely diagnoses' held true and in 13 of 17 the 'unlikely diagnoses' were upheld (largely, but not unequivocally supporting the existing advice).

Despite the "reasonable" sample size, policy makers were cautioned against relying solely on these results to refine national guidance for several reasons. These included small numbers in certain clusters, the data all being from a single Trust, the simplistic method and somewhat arbitrary rates used to determine agreement with national guidance, and the possibility of inaccurate cluster allocations/diagnoses. However, perhaps the most significant limitation was that the sample was limited to inpatients, despite the majority of UK mental healthcare being community-based. The reason for this was largely practical, in that very few community patients had a diagnosis recorded. In many ways, this meant that, whilst the study met its aims, its actual usefulness was quite limited. In this regard, it is important to recognise that (as discussed previously) most MH payment systems utilise psychiatric diagnoses. Dismissing these in favour of a needs-led approach had proved highly controversial with, for example, The Royal College of Psychiatrists formally withdrawing support for the approach (Royal College of Psychiatrists, 2014). Consequently, in addition to its explicit aims, part of the rationale for this publication was to highlight how needs-based classification complemented (rather than competed) with diagnoses.

In summary, therefore, co-authoring this article with a well-respected and well-published psychiatrist was intended to demonstrate the viability, validity and benefits of combining needs ratings with diagnoses. It also provided a methodology that could be applied to the national (inpatient and community) data available to policy makers. In short, with Self *et al's.* (2008) model criticised for a lack of academic rigour, this was an attempt to 'fight fire with fire'.

6.3 Painter, J., Trevithick, L., Hastings, R., Ingham, B., and Roy, A. (2016) ‘Development and validation of the Learning Disabilities Needs Assessment Tool (LDNAT), a HoNOS-based needs assessment tool for use with people with intellectual disability’, Journal of Intellectual Disability Research, 60(12), pp. 1178–1188.

A needs-led approach to specialist ID service provision is becoming increasingly common (Parmenter and Riches, 2002). There are, however, different types of need including 'normative' (a professional's comparison to a notional standard), 'felt' (the patient's perception), 'expressed' (the patient's request for help with their felt needs), and 'comparative' (the difference between care received/provided and the norm for that patient group) (Bradshaw, 1972). Each subtype has advantages, disadvantages and clinical tools developed to aid its measurement. Few, if any MH needs assessment tools capture issues more traditionally associated with ID but a number of ID-specific tools do capture MH needs.

Having witnessed first-hand some benefits of needs-led assessment and service provision in mainstream psychiatry, the aim of this research was to adapt/extend an existing mental health needs assessment tool to capture the full range of needs experienced by individuals accessing specialist ID services in the UK. There were practical reasons for taking this approach (rather than creating an entirely new tool). However, there was also an important philosophical stance involved (i.e. that the ID practitioners involved, all believed individuals should be able to access and receive treatment from the service best placed to meet their needs). By having a shared tool which both psychiatric and ID services could use to summarise patient needs they each typically encountered, it was hoped that the somewhat arbitrary and often unhelpful service boundaries might be blurred.

Initially a multi-disciplinary group of specialist ID practitioners reviewed the existing MH tool, the MHCT (Self *et al.*, 2008), to identify any needs that they encountered during their clinical practice that were not adequately captured. A five-point scale was then developed for each missing need (e.g. social communication difficulties, and seizures), creating an extended version of the tool for use in specialist ID services (the LDNAT).

Following training, staff from six Trusts used the LDNAT to summarise 2063 assessments of 1692 individuals. For 160 of these cases, an additional six validated assessment tools were also independently rated. Unlike the more holistic LDNAT, each tool covered a specific treatment domain (e.g. challenging behaviours, physical health, or Autistic Spectrum Disorder symptomology). The resulting data were then used to validate the new tool. Specifically, this involved assessment of the LDNAT's item redundancy and relevance, construct validity, internal consistency, test-retest reliability, and concurrent validity.

In brief, results were favourable with the exception of a lack of significant correlations between the LDNAT and the Psychiatric Assessment Schedules for Adults with Developmental Disabilities (PAS-ADD) checklists (Moss *et al.*, 1998). Findings were, however, subject to a number of caveats. Firstly, the 'real world' cascade approach to training may have led to data quality issues. Secondly, the sample was not randomly selected and may not have been representative of the wider population who access specialist ID services, or indeed the majority of individuals with ID who do not require specialist healthcare. Thirdly, the inter-rater reliability testing was on a small scale (n=27) and compromised by an inability to identify individual raters. Also, some of the additional measures, whilst valid, had known limitations but were still selected due to a lack of suitable alternatives. Finally, the LDNAT's three-component structure, identified through Principal Component Analysis (PCA) was merely a preliminary finding requiring replication and further investigation.

Overall, extending the MHCT to create the LDNAT led to additional challenges that would not have occurred if a new, bespoke tool had been created. These included copyright restrictions on re-wording the original scales and some staff concerns that a MH tool was being imposed on ID services. These disadvantages were, however, outweighed by the advantages of creating a single tool and thus a common language for both MH and ID practitioners to use when discussing the normative needs of individuals seeking to access their services.

6.4 Painter, J., Trevithick, L., Hastings, R., Ingham, B., and Roy, A. (2017) 'The extension of a set of needs-led mental health clusters to accommodate people accessing UK intellectual disability health services', Journal of Mental Health, Mar(2), pp 1-9.

This paper logically followed Paper 3, addressing many of the same concerns and gaps in the literature. Just as work to create the LDNAT involved extending an existing mental health tool (the MHCT), this research extended the coverage of the needs-led MH clusters that were developed to sub-divide MH service users into groups with similar types, severities and combinations of needs. Consequently, to ensure consistency and a seamless extension, much of this work replicated Self *et al's.* (2008) original methodology.

Ultimately, this study utilised the same staff, service users and data as the preceding study with one significant addition. After each LDNAT rating, the assessing staff allocated individuals either to an existing MH clusters, or to a pick-list of presentations more traditionally associated with ID, that had been generated through a consensus approach by ID staff.

In stage 1, 28% of the cases were allocated to an existing cluster, indicating the primary need was mental health-related. As these clusters were nationally mandated, there was no opportunity to revise them. Consequently, these data were excluded from the subsequent cluster analysis. Rather than being seen as problematic, this was deemed to be encouraging and supportive of the notion that there were overlapping needs between the two service user groups. The remaining assessment results (of individuals inadequately described by the existing MH clusters) were subjected to cluster analysis whereby five naturally existing groupings were identified.

All available assessment and demographic data was then used to produce vignettes for each cluster. Specialist ID practitioners reviewed these results in multi-disciplinary workshops and, as in Self et al.'s original project, the clusters were iteratively adjusted to optimise the balance between statistical robustness and clinical utility. Finally, profile sheets (similar to figure 3.1) were developed for each of the 9 new clusters before they were added to the existing 21 to produce a set of descriptors thought to describe the needs of most people accessing specialist ID services.

Coverage was confirmed through the project's second phase where a further 2063 unique LDNAT assessments and cluster allocations were recorded. As with phase 1, the original MH cluster allocations were removed prior to analysis. After reviewing staff's feedback regarding how well each new ID cluster described the individual's needs, one cluster was 'dispersed' across the remaining eight. The finalised clusters were then subjected to different statistical and clinical validity checks before being deemed satisfactorily robust.

Overall, the new clusters covered 83.4% of the ID cases with no other homogenous groupings apparent in the data. In terms of overlap, just 10% of the cases were found to have a LDNAT rating that could potentially fit the defined ranges for multiple clusters. Repeating statistical cluster analysis with this new block of LDNAT data yielded similar results to phase 1, indicating an encouraging degree of replicability and stability. Finally, analysis of demographic, other clinical information, goodness of fit indices and each clusters' relationships to other validated measures demonstrated clinical face validity and utility.

Several noteworthy points arise from this paper. Firstly, findings from both phases confirm that a significant proportion of people accessing specialist ID services presented primarily with MH needs, to some degree validating the initial decision to build upon the existing MH work. The end result was a seamless continuum of clusters extending from traditional MH needs, through various co-morbid presentations to primarily ID-related needs.

Fundamentally, this confirms the existence of statistically-robust, needs-based groupings that have resonance with clinical practice and the viability of classifying people accessing specialist ID healthcare by their needs. Lastly, the fact that staff could identify no clinically significant needs for 30% of the people in specialist ID services does not, in itself, mean they should not be receiving a service but definitely suggests further investigation at a local level is warranted.

This was a multi-site, mixed methods project, undertaken in a complex, politically-charged environment. Staff's participation (involving significant time and effort) was entirely voluntary and hence certain compromises were necessary to secure engagement. For example, where Self et al.'s original methodology involved individual case presentations to ensure clusters were representative, this project used aggregated clinical information to be time-efficient and hence less burdensome for staff to review. Also, as alluded to earlier, staff training in the use of the LDNAT varied in quality due to the need for a cascade model to cover all localities. Finally, given its particular importance in the field of ID (Walmsley, 2004) a weakness in the write up, (rather than the research itself) was the lack of detail provided about the service user and carer involvement in the work.

Reflecting again on the author's learning, this work could have been more clearly described but, given the journal's word restriction, the project's complexity, and that the paper was one of the earliest written, it none-the-less provides a coherent account of the work.

6.5 Painter, J., Hastings, R., Ingham, B., Trevithick, L., and Roy, A. (2018) ‘Identifying needs-based groupings among people accessing intellectual disability services', American Journal of Intellectual and Developmental Disabilities.

The majority of published accounts of subtyping people with ID through cluster analyses have been undertaken on children with autism. The wide age-range of participants in these studies make it difficult to compare findings (Beglinger and Smith, 2001). However, studies tend to identify a relatively small number of clusters (3-4), typically distinguished by level of intellectual impairment. Studies of adults with ID identified similar numbers of clusters but still tended to reduce the sample's homogeneity (e.g. by diagnosis, IQ or type of presenting problem) prior to analysis.

Unlike these earlier studies, and indeed Paper 4 in the series, this study describes the outputs of cluster analyses that utilised a wide range of presentations (i.e. regardless of diagnosis, level of intellectual impairment, or clinical problem). Its aim was to analyse the data derived from individual LDNAT ratings to identify (normative) needs-based groupings/clusters of potential interest to a wide range of stakeholders for a variety of applications.

Demographic, LDNAT, and other clinical data for 1,692 individuals from 6 NHS Trusts were used, 160 of whom had also been rated with six other condition-specific measures. Cluster analyses (Ward's method then k-means) were performed on the full sample before using data gathered from the 160 individuals with additional independently-rated measures to validate these results.

Following statistical and clinical review, a six cluster solution was favoured. These ranged from one "low need" cluster (where 20 of the 23 LDNAT scales' mean ratings were 0) through two "moderate need" clusters to three "high need" clusters focused on physical health, mental health, or challenging behaviours and autism. Face validity was confirmed by reviewing the clinical data available for members of each cluster (e.g. diagnoses, prescribed medication, and type of intervention received). Statistical validity was demonstrated by confirming the differences between each cluster, as measured by the six independently rated measures.

The detection of 6 clusters is broadly consistent with other studies, in that this project did not reduce the sample's heterogeneity before performing cluster analyses. Further work is required to confirm the utility of these findings but, in principle, this consistent way of identifying type, complexity and severity of need has multiple applications. At an individual level, tracking changes in need over time could help gauge the success (or otherwise) of care/treatment. When aggregated, these types of data could help healthcare providers to better understand the demand for services, informing staff training and service reconfiguration. Equally, commissioners could use these data to benchmark/ compare numerous aspects of the services they purchase.

In addition to the potential data quality issues identified in Papers 3 and 4, completeness rates varied considerably for some data items used to describe the characteristics of each cluster. Also, the sample was limited to users of specialist ID services (rather than the wider population of people with ID) and, even then, convenience sampling meant participants were not necessarily representative of this subset. Finally, in addition to these frequently encountered research limitations, the LDNAT rated normative needs (i.e. adopting a deficit model) rather than a more contemporary strengths-based approach and the rating of support needs (Thompson *et al.*, 2004).

Despite these limitations, the project had two main benefits over most previous studies. First, the sample was not restricted to a particular diagnostic group/presentation, and, second, the resulting clusters were validated with independent data as advocated by Clatworthy *et al.*, (2005).

6.6 Painter, J., Hastings, R., Ingham, B., Trevithick, L., and Roy, A. (2018) ‘Associations between mental health problems and challenging behavior in adults with intellectual disabilities: A test of the behavioral equivalents hypothesis.', Journal of Mental Health Research in Intellectual Disabilities.

The high prevalence of mental health problems and challenging behaviours, both separately and concurrently in people with ID is well recognised (Cooper *et al.*, 2007b; Pruijssers *et al.*, 2014). However, less well understood is the relationship between these two phenomena (Melville *et al.*, 2016). Emerson (2001) concisely articulated the main hypotheses. Firstly, he posited that MH problems may maintain pre-existing challenging behaviours. For example, a depressed person might lack the motivation to engage socially and may equally have learned that exhibiting certain behaviours typically leads to their isolation from others. In this way, their behaviours may be reinforced. Secondly, Emerson suggests that, in individuals who struggle to express their emotions, challenging behaviours may be secondary features of MH problems. For instance, somatic symptoms of depression (aches and pains) could result in sleep disturbance, agitation and other challenging behaviours. Finally, the hypothesis tested in this paper is that, in individuals with more severe ID, challenging behaviours may be atypical manifestations of a mental illness. The rationale Emerson cites is the parallels between the presentation and pharmacological treatments of obsessive compulsive disorders and some self-injurious behaviours. Since then, evidence has been produced to support each of these hypotheses but, from a brief review of the literature they all seem equally plausible.

The aim of this research was, therefore, to establish whether there were significant associations between mental health problems and 4 different ratings of challenging behaviour. Additionally, the degree to which any associations were moderated (affected) by the level of ID would be considered.

The sample was 160 individuals with ID who had been rated with 5 different condition-specific measures as part of their referral into specialist ID services. The resulting data were analysed using methods specifically designed to elicit a variable's interaction with independent variable(s) as well as its effect on dependent variable(s) (as per the “behavioural equivalents” hypothesis). In this instance, level of ID was inputted as the moderating variable; level of mental illness as the independent variable and different measures of challenging behaviour as dependent variables. The statistical modelling also controlled for a number of factors that the literature suggested could be influential (i.e. age, gender, severity of autism, and severity of physical health problems.)

The main results of these analyses were that people with more severe mental health problems exhibited more challenging behaviours but that this association was only statistically significant for individuals with more severe ID. In this way, findings were strongly supportive of Emerson's (2001) behavioural equivalents hypothesis.

Although many of the methodological weaknesses in previous studies were avoided, sample size was modest and skewed toward more able participants. In conjunction with the cross-sectional design, this meant that causality could not be unequivocally confirmed (Grove, Gray and Burns, 2015). That said, findings added to the existing literature by incorporating the moderating effect of the level of ID and by considering different aspects of challenging behaviour rather than just a single type or an overall rating. Clinically, this highlighted the need for vigilance and openness to the possibility that people with severe ID may benefit from relatively straightforward treatment for mental health conditions prior to or alongside more complex behavioural interventions.

From a personal perspective, the statistical techniques utilised here were considerably more advanced than those learnt on the author's MSc study and required additional, self-directed study.

6.7 Painter, J., Trevithick, L., Hastings, R., Ingham, B., and Roy, A. (2017) ‘Correlates for the risk of specialist ID hospital admission for people with intellectual disabilities: Development of the LDNAT Inpatient Index', Tizard Learning Disability Review, 23(1), pp.42-50.

The final paper featured in this thesis was set against the backdrop of a sustained national drive to reduce specialist inpatient care for people with ID. In recent years, aspirations have become more ambitious with the current programme anticipating a "radical reduction in beds" (Department of Health, 2012b). Despite the shortcomings of this programme (National Audit Office, 2017; NHS Digital, 2017), early identification and proactive intervention with people with ID at risk of hospitalisation is beneficial to all parties (Collins, 2015; Modi *et al.*, 2015). However, the reasons for admission, and the process itself are complex, multi-facetted and not fully understood (Oxley *et al.*, 2013). Thus, this study aimed to create a clinically useable risk index of admission to specialist ID impatient facilities.

From analysis of LDNAT data, 18 of its 23 scales differed significantly between the sample's 84 inpatients and 1591 non-inpatients. Using the summed totals of these 18 scales, a receiver operating characteristic (ROC) curve was produced that encapsulated 86% of the cases. A number of recognised methods were then used to identify the optimal cut off point on this LDNAT inpatient risk index (i.e. 22.5 on a range of 0-72). In practical terms, using this score, 68% of inpatients and 81% of non-inpatients were correctly identified.

The viability of the LDNAT in clinical practice has already been established and hence this simple calculation has potential for use in community settings to identify individuals most at risk of admission, and hence most in need of proactive intervention. Aggregated risk index data could also be of interest to commissioners wishing to benchmark services they purchase.

Despite triangulating several recognised statistical techniques, this research was hampered by the small amount of inpatient data, an inability to control the timing of assessments in each person's treatment pathway, and its cross-sectional design. Never-the-less, its findings are encouraging and, worthy of further (longitudinal) investigation.

6.8 Critical appraisal

The annotated bibliography forming the bulk this section briefly describes the aims, methods, findings and relevance of each paper individually. All research has weaknesses (Gray and Grove, 2017) and hence each annotation also includes a narrative account of that study's main limitations. Critiquing literature is however challenging and, objective criteria in the form of appraisal checklists can be helpful (Krainovich Miller, 1994). Therefore, to supplement these annotations, the lead author completed Table 6.1 below to provide a visual representation of each paper's strengths and weaknesses against a set of objective criteria. This particular quality appraisal checklist (derived from Jackson *et al,* 2006) is used by the National Institute for Health and Clinical Excellence (NICE, 2012) to evaluate quantitative studies.

Although an appraisal tool for qualitative research was used to inform the annotated appraisal of Paper 1 (Critical Appraisal Skills Program, 2017). As it includes different criteria/questions, meaningful comparison of this paper to the remainder in Table 6.1's simple visual format was impractical. Of the remainder, these tabulated results show that the population and sample were adequately described but that, on occasion, there was a lack of detail regarding how representative the participants were of these wider groups. Convenience (rather than probability) sampling adversely affected ratings of participant selection methods, however, the choice of variables was consistently sound and, the multi-site collection of these data resulted in strong scores on each paper's relevance to UK healthcare more widely. The outcomes ratings (checklist section three), were impacted by potential data quality issues that are frequently encountered in naturalistic studies, i.e. staff training and variable data completeness. However, as these were openly discussed in each paper, respectable ratings were still achieved. In general, the analyses undertaken in each paper were robust. Sample sizes were always reported but formal power calculations were lacking. This could be viewed as an inevitable artefact of the naturalistic nature of the studies but has, none-the-less, been taken into account in section four's ratings.

Overall (section 5), there were no major failings in reliability, validity, or overall quality. Where shortcoming existed, they were deemed unlikely to significantly affect findings. All studies were judged to be relevant to the wider NHS but their generalisability was limited by their cross-sectional designs.

Table 6.1: Critical appraisal checklist for publications.

Critical Appraisal Checklist		**Paper**						
Section 1: Population		**1**	**2**	**3**	**4**	**5**	**6**	**7**
1.1 Is the source population or source area well described?	Was the country (e.g. developed or non-developed, type of health care system), setting (primary schools, community centres etc.), location (urban, rural), population demographics etc. adequately described?	NA	++	++	++	++	++	++
1.2 Is the eligible population or area representative of the source population or area?	Was the recruitment of individuals, clusters or areas well defined (e.g. advertisement, birth register)? Was the eligible population representative of the source? Were important groups under-represented?	NA	+	+	+	+	+	+
1.3 Do the selected participants or areas represent the eligible population or area?	Was the method of selection of participants from the eligible population well described? What % of selected individuals or clusters agreed to participate? Were there any sources of bias? Were the inclusion or exclusion criteria explicit and appropriate?	NA	+	+	+	+	+	+
Section 2: Method of selection of exposure (or comparison) group								
2.1 Selection of exposure (and comparison) group.	How was selection bias minimised?	NA	+	+	+	+	+	+
2.2 Was the selection of explanatory variables based on a sound theoretical basis?	How sound was the theoretical basis for selecting the explanatory variables?	NA	++	++	++	++	++	++
2.3 Was the contamination acceptably low?	Did any in the comparison group receive the exposure? If so, was it sufficient to cause important bias?	NA	NA	NA	NA	NA	NA	NA
2.4 How well were likely confounding factors identified and controlled?	Were there likely to be other confounding factors not considered or appropriately adjusted for? Was this sufficient to cause important bias?	NA	+	+	+	+	++	+

Section 3: Outcomes		1	**2**	**3**	**4**	**5**	**6**	**7**
3.1 Were the outcome measures and procedures reliable?	Were outcome measures subjective or objective (e.g. biochemically validated nicotine levels ++ vs self-reported smoking −)? How reliable were outcome measures (e.g. inter- or intra-rater reliability scores)? Was there any indication that measures had been validated (e.g. validated against a gold standard measure or assessed for content validity)?	NA	+	+	+	+	+	+
3.2 Were the outcome measurements complete?	Were all or most of the study participants who met the defined study outcome definitions likely to have been identified?	NA	++	+	+	+	+	+
3.3 Were all the important outcomes assessed?	Were all the important benefits and harms assessed? Was it possible to determine the overall balance of benefits and harms of the intervention versus comparison?	NA	+	+	+	+	++	+
3.4 Was there a similar follow-up time in exposure and comparison groups?	If groups are followed for different lengths of time, then more events are likely to occur in the group followed-up for longer distorting the comparison. Analyses can be adjusted to allow for differences in length of follow-up (e.g. using person-years).	NA	NA	NA	NA	NA	NA	NA
3.5 Was follow-up time meaningful?	Was follow-up long enough to assess long-term benefits and harms? Was it too long, e.g. participants lost to follow-up?	NA	NA	NA	NA	NA	NA	NA

Section 4: Analyses		1	2	3	4	5	6	7
4.1 Was the study sufficiently powered to detect an intervention effect (if one exists)?	A power of 0.8 (i.e. it is likely to see an effect of a given size if one exists, 80% of the time) is the conventionally accepted standard. Is a power calculation presented? If not, what is the expected effect size? Is the sample size adequate?	NA	+	+	+	++	++	+
4.2 Were multiple explanatory variables considered in the analyses?	Were there sufficient explanatory variables considered in the analysis?	NA	++	++	++	+	++	++
4.3 Were the analytical methods appropriate?	Were important differences in follow-up time and likely confounders adjusted for?	NA	+	++	++	++	++	++
4.4 Was the precision of association given or calculable? Is association meaningful?	Were confidence intervals or p values for effect estimates given or possible to calculate? Were CIs wide or were they sufficiently precise to aid decision-making? If precision is lacking, is this because the study is under-powered?	NA	++	++	+	NA	++	++
Section 5: Summary								
5.1 Are the study results internally valid (i.e. unbiased)?	How well did the study minimise sources of bias (i.e. adjusting for potential confounders)? Were there significant flaws in the study design?	NA	+	+	+	++	++	+
5.2 Are the findings generalisable to the source population (i.e. externally valid)?	Are there sufficient details given about the study to determine if the findings are generalisable to the source population? Consider: participants, interventions and comparisons, outcomes, resource and policy implications.	NA	+	+	+	+	+	+

Key to ratings for sections 1-4	
++	Indicates that for that particular aspect of study design, the study has been designed or conducted in such a way as to minimise the risk of bias.
+	Indicates that either the answer to the checklist question is not clear from the way the study is reported, or that the study may not have addressed all potential sources of bias for that particular aspect of study design.
-	Should be reserved for those aspects of the study design in which significant sources of bias may persist.
NR	Should be reserved for those aspects in which the study under review fails to report how they have (or might have) been considered.
NA	Should be reserved for those study design aspects that are not applicable given the study design under review (for example, allocation concealment would not be applicable for case control studies).

Key to ratings for section 5	
++	All or most of the checklist criteria have been fulfilled; where they have not been fulfilled the conclusions are very unlikely to alter.
+	Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.
-	Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.

In addition to these general observations, the nature of Papers 4 and 5 makes an additional appraisal worthwhile. Both employed cluster analyses to produce clinically and statistically meaningful cluster solutions for two different sets of LDNAT data. Consequently, these papers have also been considered against an adapted version of Aldenderfer and Blashfield's (1984) quality criteria, from Clatworthy *et al's.* (2005) appraisal of 59 accounts of cluster analysis in healthcare (Table 6.2). N.B. these criteria have been graded according to the rating guidance in Table 6.1 above.

Table 6.2: Quality appraisal checklist for Papers 4 and 5

Criterion	**Paper**	
	4	**5**
The statistical package used for the cluster analyses is reported	++	++
The method used to assess similarity is reported	++	++
The cluster method is reported	++	++
The procedure for determining the number of clusters is reported	+	+
Evidence for the validity of the clusters is reported	++	++

Positively, when judged against these five criteria, Papers 4 and 5 are still of a high quality, with the only significant area of weakness common to most other accounts (Clatworthy *et al.*, 2005). Having considered each paper individually, the next section will synthesise their findings, limitations and implications.

7.0 Discussion

This section summarises the key findings and discussion points from each paper (Table 7.1) before emergent themes, weaknesses and their collective contribution are considered.

7.1 Findings

Even before considering the papers in detail, it is interesting to note that, despite each one being concerned with quite a fundamental issue within the field of ID, (e.g. identifying groups of service users with similar needs, considering what drives challenging behaviours, or reducing avoidable admissions) they all address a clear gap in the existing literature. The LDNAT was, of course, newly developed but other needs assessments are available (see NIMHE, 2008), raising the question as to why such gaps still exist. One reason may be the complexity and idiosyncratic nature of these topics (Hemmings *et al.*, 2013). However, working with the Clinical Information Officers from the 18 participating organisations, it was obvious that UK specialist ID services lag behind mainstream MH services in their use of a nationally-defined common data set. Given that the majority of research in this thesis involved the retrospective (and often secondary) use of clinical data, this disparity may be contributing to the dearth of large-scale, multi-site, quantitative research into these topics.

Table 7.1: Summary of the key findings and discussion points

Paper	Summary of key findings and discussion points from each paper
1	• HoNOS is reliable, valid and clinically useful but, in need of update and improvement • Supplementing the glossary with training improves inter-rater reliability • The cognitive impairment scale, in particular, needed revision as it was too dementia-focused • The non-accidental self-injury scale explicitly excluded self-injurious behaviours attributable to ID.
2	• Cluster allocation accuracy of 68% and coverage of 90% was attained locally for psychiatric inpatients • Statistically significant associations between cluster super classes and broad diagnostic categories were present • There were clinically intuitive relationships between clusters and psychiatric diagnoses but these were not 1:1 mappings, re-enforcing the benefit of using both systems in combination • Cluster data could help identify the skills needed by different groups of staff, and inform their post registration training • Substance misuse diagnoses were spread across most MH clusters.
3	• All MH scales were used on at least one patient in the ID sample but scales for: suicide and self-harm, substance misuse, hallucinations/ delusions, and strong unreasonable beliefs were less relevant • ID staff felt additional scales were required to capture : self-injurious behaviours, problems with eating and drinking, social communication difficulties, communication problems, and seizures • The resulting tool (the LDNAT) was valid, reliable and had clinically intuitive associations with other clinical measures • The LDNAT had three subscales (Mental Health and Wellbeing, Developmental Needs and Challenging Behaviours) • The LDNAT could facilitate holistic assessment of people with ID and MH problems.
4	• After removing primarily mental health-related cases, five statistically meaningful groups were apparent which were subdivided to provide more clinical utility • The original mental health clusters and new ID clusters had statistically different LDNAT total and (two) subscale scores • 83% of cases were allocated to a cluster • The new ID clusters fell into dimensions around challenging behaviour, physical health, ID and autistic spectrum disorder • The clusters' fuzzy boundaries could help address problems encountered in clinical practice with the more categorical diagnostic approach to ID. • Clinically intuitive differences between the clusters in terms of mean scores on the LDNAT and other measures were apparent • Cluster data could help identify the type and level of demand for services, the skills needed by different groups of staff, and inform their post registration training.

Paper	Summary of key findings and discussion points from each paper
5	• When the full sample (MH and ID presentations) was analysed, six statistically meaningful groups were apparent • These clusters differed along key dimensions including: challenging behaviours, ID, autistic spectrum disorder (ASD) and physical health • Use of these clusters could facilitate more transparent treatment options for service users • Cluster data could help identify type and level of demand for services, differences in case mixes, the skills needed by different groups of staff, and inform their post registration training.
6	• Internal consistency of the BPI-Short Form's self-injurious behaviour subscale was weak in this sample • Mental health problems were associated with: self-injurious behaviours, stereotyped behaviours and overall challenging behaviours, but only in the more severely cognitively impaired service users • Autistic spectrum disorder severity was positively associated with overall levels of challenging behaviour • There is a need for clinicians to screen and (where appropriate) treat people with more severe ID for mental health problems prior to undertaking more complex and costly behavioural analyses and interventions.
7	• It was possible to distinguish inpatients from the remainder of the sample using the total of the 18 LDNAT scales that differed significantly between the two groups • The ratings of: substance misuse, cognitive problems, physical health, seizures, and problems with eating and drinking did not differ between inpatients and the remainder of the sample • The LDNAT could be useful in identifying individuals on community caseloads who are most in need of proactive intervention to prevent admission • LDNAT data could help compare the level of complexity that triggers transfer between different services and inform staff training programmes for those services.

Turning then to the findings themselves (Table 7.1), it is clear that the needs captured by the original MH tool were also relevant to individuals accessing specialist ID services, with Paper 3 finding that the full range of each MHCT scale had been used. Some needs were less frequently encountered (e.g. substance misuse) but, there was definite overlap between the needs of people accessing MH and ID services. In some ways this justifies the aspirations of the ID practitioners involved at the outset of the work i.e. to create a universal tool. There were, however, needs that ID staff suggested were missing from the MHCT including self-injurious behaviours, social communication difficulties, seizures, and physical problems with eating or drinking. This might suggest that specialist ID service users have more diverse needs than those entering secondary mental healthcare but, could equally be an artefact of the augmentation approach taken to its development, rather than reflecting a true difference. Regardless of this, these papers confirm the feasibility of capturing a wide range of objective needs in a relatively brief, valid and reliable measure (the LDNAT), and that the resulting data can have multiple applications.

Papers 4 and 5 concern the application for which the LDNAT was primarily developed, i.e. identifying needs-based service user-groupings. Table 7.2 below highlights how the two cluster solutions, derived from the two different blocks of data (phases 1 and 2 of Paper 4), compare. N.B. Paper 4's cluster analysis excluded individuals deemed to have a primary MH need whilst Paper 5's included all cases.

Table 7.2: Comparison of cluster solutions in Papers 4 and 5 (including relatively high and low scoring LDNAT items)

Cluster:		**4D**	**5E**	**4E**	**5F**	**4A**	**5A**	**MH**	**5D**	**4C**	**5C**	**4B**	**5B**
Percentage of sample:		22%	28%	13%	18%	14%	19%	26%	11%	10%	11%	15%	13%
Relatively high and low scoring LDNAT items:	**Overactive, aggressive, disruptive or agitated behaviour**		L					Allocated to the original MH clusters, hence excluded from Paper 4's analysis	H	H		L	L
	Non-accidental self-injury								H				
	Problem drinking or drug taking												
	Cognitive problems	L	L	H							H	H	H
	Physical illness or disability problems					L						H	H
	Hallucinations or delusions								H				
	Depressed mood								H	H		L	
	Other mental and behavioural problems								H	H	H	L	L
	Relationships		L						H	H	H	L	
	Activities of daily living	L	L		L					H	H	H	H
	Living conditions								H	H			
	Occupation and activities								H				
	Strong unreasonable beliefs								H				
	Non-accidental self-injury (associated with cognitive impairment)	L								H	H	L	
	Physical problems with eating and drinking											H	H
	Agitated behaviour/expansive mood		L		H				H	H	H	L	L
	Repeat Self-Harm			H	H				H	H		L	
	Safeguarding other children and vulnerable dependent adults	L		H					H	H	H	L	
	Engagement		L						H	H	H		
	Vulnerability	L	L	L						H	H	H	H
	Social communication difficulties	L	L		L	H	H			H	H		
	Communication problems	L	L	L	L	H					H	H	H
	Seizures	L										H	H
Mean total LDNAT:		15.1	11.5	24.3	20.1	25.1	23.0		36.0	38.6	37.4	24.6	25.7

Sequencing and colour coding both sets of clusters shows, the 26% of 'mental health' cases excluded from Paper 4's analysis appear to be recreated as the smaller cluster 5D (high MH needs) in Paper 5, with the remainder seemingly distributed across the low and moderate need clusters in this paper (5E, 5F and 5A). Taking this into account, the ID cluster 'pairings' account for similar proportions of their respective samples, show similar patterns of relatively high and low scoring needs, as well as their ranking of overall need (mean total LDNAT scores). Speece (1994) states that cluster analysis is highly subjective compared to other statistical techniques. The stability/replicability of cluster solutions is therefore a key indicator of their validity (Clatworthy *et al.*, 2005). Clearly Table 7.2 is a relatively crude comparison; however, it confirms an encouraging degree of similarity, stability and hence validity. This suggests these groupings are, at least, worthy of further investigation.

Other applications identified for the LDNAT and its data varied by stakeholder. It's use at referral into services could help ensure **service users** receive a holistic assessment of their needs (Paper 3) and lead to a clearer, more informed choice of interventions to meet these needs (Paper 5). Totalling a subset of the LDNAT scales could help **practitioners** prioritise individuals on community caseloads most at risk of admission to specialist ID inpatient settings (Paper 7) and, subject to further investigation, to monitor the effectiveness of their interventions (Paper 3). Analysis of these data could also help support/refute clinical hypotheses such as the relationship between mental health and challenging behaviours in people with ID (Paper 6). **Service providers** could aggregate LDNAT and/or cluster data to identify the type and level of demand for services to inform staff training programmes and service reconfigurations that are tailored to meeting these needs (Papers 4, 5 and 7). Finally, **commissioners** could utilise these data to compare the case-mix complexity of services (Paper 5) when judging their cost effectiveness.

Although many of these applications for the LDNAT have yet to be tested, parallel work with the MHCT suggests they have real potential. The ID-focused Papers (3-7) are relatively recent publications but are already generating interest, as evidenced for example, by their Research Gate statistics. An additional, more tangible impact has been Health Education England (HEE) commissioning the use of LDNAT data to produce an empirical training needs analysis for specialist ID services. Given this positive attention, the full suite of publications is due to be presented to HEE for further consideration.

7.2 Limitations

All research has weaknesses, especially when set in routine clinical practice which (rightly) prioritises patient care. Recognising limitations is key to appraising quality, but also to planning future studies (Grove, Gray and Burns, 2015, p366). Having considered weaknesses paper by paper in section 6, this section highlights emergent themes.

Firstly, given that these studies were primarily retrospective analyses of routinely collected clinical information; the old adage of "*garbage in = garbage out*" applies. Data completeness and quality were consistently highlighted as potential weaknesses in Papers 2-7. Mitigation, however, included: standardised rater-training materials, selecting additional measures suited to untrained informant rating, and carefully reporting all data. Whilst the success of these actions is hard to quantify, the LDNAT demonstrated acceptable inter-rater/test-retest reliability, the cluster solutions a promising degree of stability and, most findings an encouraging level of clinical face validity.

Secondly, only a small amount of longitudinal data was captured, hence the quantitative studies (Papers 2-7) were all cross-sectional designs. Statistical approaches were carefully selected to optimise findings but, this over-arching design feature prevented cause and effect being definitively established.

Generalisability was also affected by the sample's characteristics, (which consisted solely of specialist ID service users and very few inpatients), meaning findings may not apply to the wider ID population. A further issue with the sample was its bias toward the mild-moderate end of ID. The LDNAT scales added to the original MH tool were primarily developed for people with more severe ID, and Paper 6 was specifically focused on this patient group but, in light of this skew, the LDNAT requires further testing with people with severe-profound ID.

The final point to note in this section concerns the amount of direct service user involvement. Publications such as: No Decision about me without me (Department of Health, 2012a) view service user involvement in healthcare as paramount. Walmsley (2004) also advocates service user involvement in research but acknowledges the limitations that cognitive impairment can have on their ability to engage in complex/abstract thinking tasks. In light of this, service user involvement was limited to the main (NHS England sponsored) project (Papers 3 and 4), where their input was truly meaningful, rather than throughout the other secondary analyses (Papers 5-7) purely in response to this rhetoric. During this early stage, several user/carer workshops were held, including two which were facilitated by an independent advocacy group. Whilst these were useful in progressing the work, Walmsley's predictions certainly held true in that participants struggled with the conceptual nature of the project and were, understandably, more interested in how ratings/clusters would translate into offers of care.

7.3 Recommendations

A number of recommendations lead logically from these papers' collective findings. From a purely theoretical perspective, larger-scale, longitudinal studies are the most obvious way to build upon the descriptive and correlational designs utilised to date (Grove, Gray and Burns, 2015, p33). Also, testing of the LDNAT's ability to capture the needs of people with severe-profound ID is indicated. These would strengthen the evidence for the LDNAT's validity (Paper 3) as well as the stability of the cluster solutions (Papers 4 and 5). Longitudinal designs would be particularly helpful to establish causal relationships between mental health problems and challenging behaviours (Paper 6). They would also be invaluable in ascertaining the LDNAT's effectiveness in identifying ID service users most at risk of subsequent hospital admission.

In reality (as previously described), how some of these findings are taken forward will depend on finances and political agendas. Paper 1, for instance, acknowledges that empirical testing of the revised HoNOS is reliant on the Royal College of Psychiatrists obtaining funding and governmental support. Early indications are that both will be secured however the current international tripartite arrangement has proved inherently challenging to navigate. Similarly, Paper 2 was primarily borne out of the MHCT's use in a new national payment system. Unfortunately, the deteriorating NHS finances have slowed its roll-out, meaning funding for a larger sample of inpatients and outpatients is now less likely.

In summary, therefore, capturing, exploring and utilising ratings of objective need (as per these studies) adds to the existing literature and offers practical benefits. The next (and final) section concludes this thesis with reflections on the personal impact of the research undertaken.

8.0 Reflections and Conclusions

I still remember reading research as a newly qualified nurse and thinking "so what?" Some 25 years later and, having produced the papers for this thesis, I now appreciate why most research has a relatively modest impact on its audience. Authoring these papers, however, means they have had each a much greater effect on me. In the sequence presented, they progress from low level evidence (structured expert opinion) through descriptive studies, to stronger correlational designs. I believe they also advance from theoretical foundations to practical applications with the potential to positively impact service users. Together, these have provided invaluable experience of 'real world research' in a politically-charged environment; requiring mastery of statistical packages, selection of, and interpretation of appropriate statistical analyses for the data/question in hand. As my nurse training omitted this, I am therefore particularly pleased to have developed my knowledge and skills in this specific area, as well as research more broadly.

In conclusion, after detailing my career, this thesis has explored aspects of needs-led healthcare for people with MH problems and/or ID. It has described and critiqued seven of my publications on this topic before explaining their significance and collective contribution to the field of ID. Undertaking these studies, and this overarching thesis, has changed my original perspective on research's impact. It has not, however, changed my belief that healthcare research should benefit service users, something which I hope this work will ultimately achieve.   The work has been challenging, protracted and, at times frustrating but also an incredibly rewarding process that I intend to build upon in the next (academic) stage of my career.

9.0 References

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10.0 Appendix: Bibliography of all publications by the author

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